How the
Health Information Act
Will Work

Alberta's Health INFORMATION Act

Alberta
HEALTH AND WELLNESS
2001

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Alberta's Health INFORMATION Act

Introduction

The Health Information Act was passed by the Alberta Legislature on December 9, 1999.

This document provides an overview of how the various provisions of the Act work together as a whole to protect an individual's privacy and put careful controls on sharing of health information. It identifies the purposes of the Act, discusses its scope of application and illustrates how the concept of controlled sharing will work.

People are encouraged to read this overview along with the entire Act and the Guide that was provided when the Act was introduced. This overview addresses many of the issues and questions that have been raised. It does not provide a detailed explanation of all aspects, terms or concepts used in the Act nor is it intended as legal advice or a legal interpretation of the Act. Work is underway on plans for implementing the legislation. Additional documents and information will be provided to guide implementation, address specific questions, and assist custodians in preparing for implementation of the new legislation.

What is the purpose of the Act?

The Health Information Act has seven key purposes:

- To establish strong and effective mechanisms to protect the privacy of individuals with respect to their health information and to protect the confidentiality of that information
- To enable health information to be shared and accessed, where appropriate, to provide health services and to manage the health system
- To prescribe rules for the collection, use and disclosure of health information, which are to be carried out in the most limited manner and with the highest degree of anonymity that is possible in the circumstances
- To provide individuals with a right of access to health information about themselves, subject to the limited and specific exceptions as set out in the Act
- To provide individuals with a right to request correction or amendment of health information about themselves
- To establish strong and effective remedies for contravention of this Act
- To provide for independent reviews of decisions made by custodians under the Act and the resolution of complaints under the Act

What is the scope of Act?

The scope of the Act reflects two essential dimensions:

- Who does the Act apply to?
- What type of information is covered under the Act?

Who does the Act apply to?

Who The Health Information Act Will Apply To:

Pharmacies/ Pharmacists
Regulated Health Professionals Paid by AHCIP
RHAs and Provincial Boards
Minister and Department (Alberta Health & Wellness)
Other Hospitals and Nursing Homes
Other Boards, Agencies, Committees etc.

Excludes - AADAC and PDD Boards

The Act applies to "custodians" of health information primarily in the publicly funded health sector. Custodians include:

- the Minister and department of Alberta Health and Wellness
- Regional Health Authorities
- the Alberta Cancer Board
- the Alberta Mental Health Board
- hospitals and nursing homes not directly operated by the health authorities or boards
- health service providers paid under the Alberta Health Care Insurance Plan (i.e. physicians, chiropractors, dental surgeons, dental mechanics, opticians, optometrists, podiatrists and osteopaths)
- pharmacists and pharmacies regardless of how they are paid
- boards, agencies, committees and other organizations to be identified in the regulations.

The Act also extends to "affiliates" of custodians. Affiliates include employees, agents, volunteers and physicians paid by a custodian or having privileges with a custodian.

Although the Alberta Alcohol and Drug Abuse Commission (AADAC) and Persons With Developmental Disabilities (PDD) Boards report to the Minister of Health and Wellness, these organizations are specifically excluded from the scope of the Act.

What types of information are covered?

What the Health Information Act Applies To:

Health Information (about an Individual)

Diagnostic, Treatment and Care Information	Registration Information	Health Service Providers
About: • Physical & mental health • A health service - Prevention, promotion protection - Diagnosis/treatment - Rehabilitation - Care for the ill, disabled, injured or dying - Pharmacy service • Donation of bodily part or substance • Drug • Health care aid, device, product or equipment • Amount of benefit paid or payable for service • Other information collected when a health service is provided	General Categories: • Demographic • Location • Telecommunications • Residency • Health service eligibility • Billing	• Demographic information • Unique number • Type of provider • Education • Continued competencies • Restrictions • Decisions of health professional bodies • Business arrangements • Employment information

Excludes - Services by ambulance attendants, AADAC and PDD Boards
- Information that is not written, photographed, recorded or stored in a record

The Act applies to health information about an individual and includes three types of information:

- **Diagnostic, treatment and care information** is the most sensitive information about an individual's health and the health services provided to that individual, including the cost of those services. While many of the rules in the Act apply to all three types of health information, the most stringent rules apply to this category.

- **Registration information** is demographic information about an individual (e.g. name, address, gender, etc.) including whether or not they are eligible to receive health services. In some cases, such as a patient or medical record, registration information about a patient is combined with information about that person's health. In other settings, the information may be maintained and used quite apart from any diagnostic, treatment and care information. Rules in the Act reflect these differences.

- **Health service provider information** is basic demographic information about health service providers working in the health system at an office, clinic, hospital, regional or provincial level. It includes information such as who the provider is, where they work, what they do, and their professional qualifications. In some cases, such as a patient or medical record, information about health service providers may be linked with identifying health information about patients. In other cases, the information is maintained and used for internal or health system management purposes, apart from any other types of health information. Rules in the Act are primarily intended to reflect cases when health service provider information is combined with other types of health information. The Act also points to other legislation as the source of other rules that may apply to health service provider information.

Information about services provided by ambulance attendants, AADAC and PDD Boards is specifically excluded from the definition of health information. As mentioned above, AADAC and PDD Boards are not subject to the Act as custodians. Ambulance services are generally operated and/or funded by municipalities in the province. Their information is subject to the Confidentiality Regulation under the Ambulance Services Act.

What is the mandate of custodians?

Custodians are Mandated to Perform a Role
Pharmacies/ Pharmacists
Regulated Health Professionals Paid by AHCIP
Roles of Custodians:
• Provide Health Services
• Determine Eligibility
• Conduct Investigations
• Conduct Research
• Provider Education
• Carry Out Purposes In an Enactment
• Internal Management
• Health System Management
RHAs and Provincial Boards
Minister and Department (Alberta Health & Wellness)
Other Hospitals and Nursing Homes
Other Boards, Agencies, Committees etc.

The custodians identified in the Act are primarily part of the publicly funded health system. They all have certain responsibilities in the health system, they are funded to fulfill those responsibilities, and they are accountable for the outcomes they achieve.

Generally, all custodians are mandated to:

- Provide health services
- Determine an individual's eligibility to obtain health services
- Investigate, review or inspect the services provided by health service providers
- Conduct research into better health practices, services or management
- Provide health service provider education
- Carry out the specific purposes identified in other legislation such as the Hospitals Act, the Public Health Act, the Cancer Programs Act and the Regional Health Authorities Act
- Manage internal operations such as plan and allocate resources, quality improvement, evaluation, obtain payment for services provided and so on

In addition, some custodians (i.e. the Minister and department of Alberta Health and Wellness, Regional Health Authorities and Provincial Boards) have broader regional or provincial responsibilities. In addition to the above list, these custodians are also mandated to:

- Plan and allocate resources on a regional or provincial basis
- Manage the health system on a regional or provincial basis
- Conduct public health surveillance to determine and improve the health of the regional or provincial population
- Develop health policies and programs on a regional or provincial basis

At the heart of the Act is a firm understanding that custodians require information in order to fulfill their mandates. Without information, they are unable to assess the outcomes of their actions, provide quality health services, or meet other expectations and responsibilities. The concept of "controlled sharing" means that custodians are permitted to obtain and use the amount and type of health information that is truly necessary for them to perform their mandate. This does not mean widespread uncontrolled sharing of an individual's most private and sensitive health information. The "necessity" test is significant. Custodians will be held accountable for their actions under the Act and will need to demonstrate their need for the information they collect and use.

What is the "controlled arena"?

The Act builds a fence, or a "controlled arena," around those custodians who are subject to the Act. Most rules apply to custodian-to-custodian interactions and activities within the controlled arena, or to the various duties and responsibilities of individual custodians. Some rules apply to the movement of information outside of the controlled arena. It is important to understand that the rules within the Act were developed for the custodians covered by the Act and operating within the controlled arena of the publicly funded health system in Alberta.

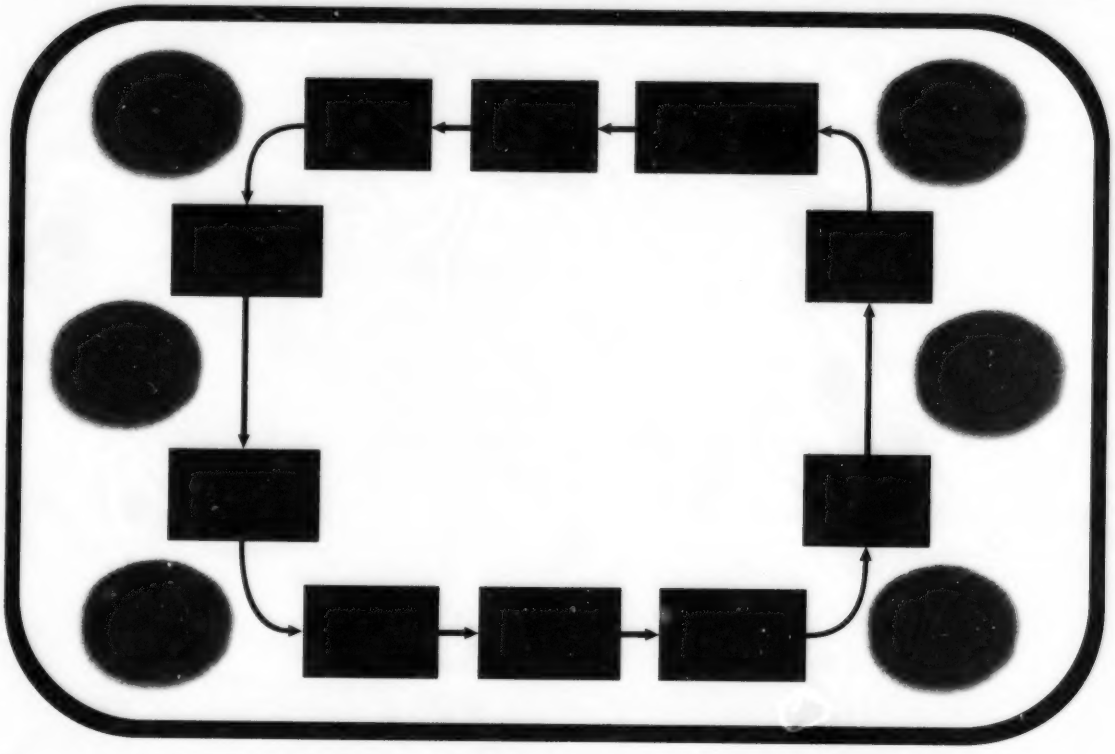
A Fence Is Constructed Around A "Controlled Arena"

Questions have been raised about why the Act does not apply to all health information about an individual that is in existence. Questions also have been raised about why the rules in the Act do not apply to insurance companies, employers or others who may want or who have individual health information. At this point, the Act applies to custodians within the public health system and to certain types of information. A three-year review of the rules and the scope is specifically required in the Act. At that time, consideration will be given to expanding the scope to include the balance of the public sector, including other government departments and schools, universities and municipalities, and to the private sector. If a decision is made at that time to expand the scope of the Act, a careful examination of the rules will be required to ensure that an appropriate set of responsibilities is established for those outside the publicly funded health sector.

How does the controlled arena work?

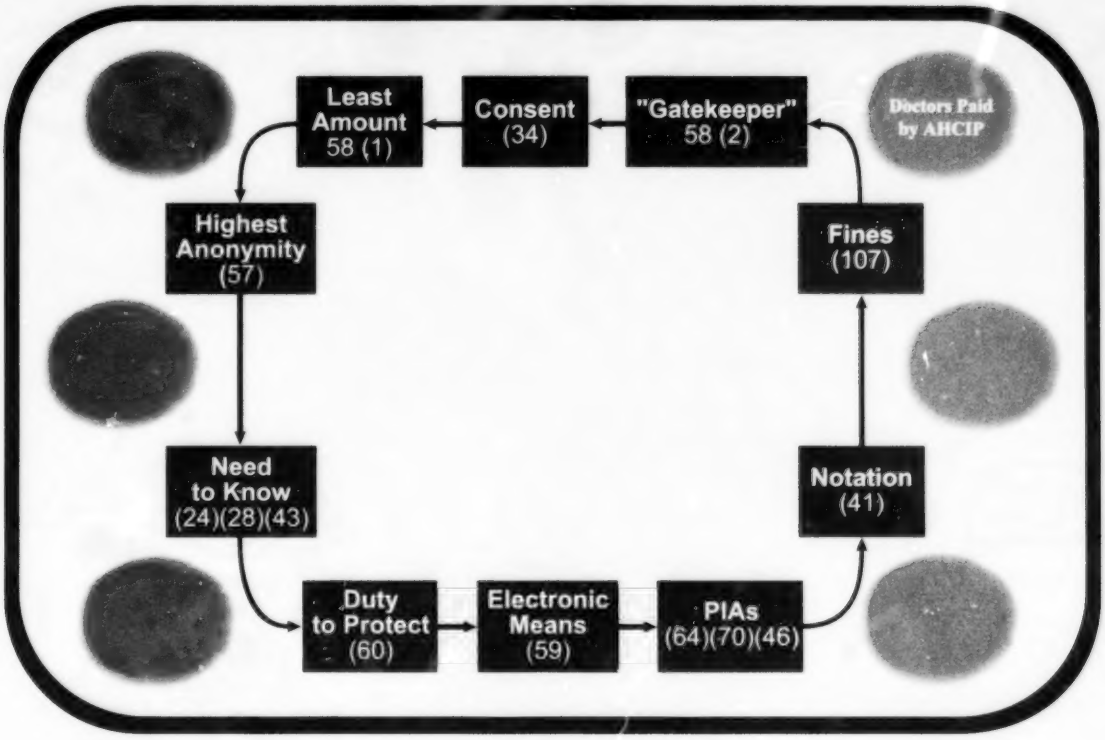
Health information is expected to move from one custodian to another within the controlled arena, but the Act does not allow a "free flow" of health information. There are ten specific barriers or constraints in the Act that serve as obstacles to the free flow of information. The set of ten barriers applies to all custodians subject to the Act, including the Minister and department of Alberta Health and Wellness. The diagram below illustrates this concept. The blue circles continue to represent the custodian types subject to the Act. The green boxes represent the constraints to the free flow of information.

Custodians and Barriers



The next diagram uses doctors paid by AHCIP as an example to illustrate how the barriers restrict the flow of information. The same barriers impact all custodians within the scope of the legislation including the Minister and the department of Alberta Health and Wellness.

Ten barriers restrict the flow of information



1. Custodian as "gatekeeper"

During the development of the Act, people said they were concerned about the privacy of their health information. They also said they do not necessarily understand or know what happens to their health information today, but they have full confidence in their physician or other custodian of the information to collect, use or disclose only the information that is appropriate and necessary. They were generally comfortable with the custodian being the trusted "gatekeeper" of their information on their behalf.

This "gatekeeper" concept is reflected in the Act in two ways. The first is that the vast majority of the disclosure provisions in the Act are discretionary. This means that when a custodian receives a request for some amount or type of health information, that custodian is expected to evaluate the request in terms of its impact on the patient, its benefit to the health system, or other criteria, and decide whether or not they will release any information in response to the request. Second, custodians are required to consider any expressed wishes of the individual patient relating to disclosure of the information. While there are some situations when a physician cannot withhold information even if a patient has made an express wish (e.g. a requirement in law or a medical emergency involving the patient), specific concerns or limited disclosure requests by patients will continue to be respected, wherever possible.

2. Consent

Consent for disclosure of information is an important consideration for custodians. The Act authorizes custodians to disclose health information with the informed consent of the individual. The consent must stipulate:

- who is to receive the information and why
- the effective dates of the consent
- specifics about what information is to be disclosed
- an indication that the individual has been made aware of the reasons why the information is needed, and
- the implications to the individual of consenting or refusing to consent.

The Act permits custodians to disclose some information in some circumstances without the consent of the individual, but those circumstances are specifically identified in the Act. In those instances, all of the other nine constraints to disclosure clearly come into effect.

3. Least amount of information

Typically, in a physician's office or a large organization like a hospital, significant volumes of health information are created and maintained. Not all of this information is relevant, important or necessary to address a specific request for information. If a custodian believes there is a need to disclose some information about a patient, or even if they are required to disclose the information, under the Act they are required to disclose the least amount possible to achieve the intended purpose. That means a physician can not (and typically currently does not) release any health information without understanding who it is going to, why it is needed and whether or not the same purpose can be achieved with less information being released. The complete patient file would be released in only very limited circumstances. If there is a need to disclose some information for a specific purpose, rather than disclosing all of the information in the file, perhaps just an indicator of a personal health number, the date of service and a code indicating the type of service could be provided.

4. Highest degree of anonymity

At one extreme, information can be fully attributed to an identifiable individual. Health information is initially collected or created in this form. Identifiers may be the person's name and address but other information (such as birth date, full postal code, personal health number, etc.), when presented together or with other information, may also identify individuals. At the other end of the continuum is totally non-identifying information about large populations or groups of people. This information is typically referred to as statistical or aggregated information. It can be virtually impossible to identify a single individual from this type of information. Between these two extremes is a range of ways that information can be made more or less identifying.

The Act requires custodians who are considering releasing some amount of health information, to release information at the highest degree of anonymity possible to achieve the intended purpose. Again, this implies that the custodian will need to understand the intended purpose and will need the tools or ability to transform information so that individuals cannot be identified. This is more readily achieved in an electronic records environment than in a paper-based records environment.

5. Need to know

Employees and agents of custodians are constrained under the Act to only collect, use or disclose identifying health information about specific individuals if their duties require the information. This means that an employee with administrative or policy roles likely would not have any access to identifying health information. Even employees or others involved in direct patient care would only have access under the Act to information about the patients they are responsible for or providing care to. They would not have broad access to all patient information. For example, an employee of the department of Alberta Health and Wellness would not be able to walk into a physician's office and demand to see health information about another individual. The "need to know" and other constraints in the Act would prevent this from happening.

6. Duty to protect

Custodians are responsible for safeguarding the health information in their possession and when it is transmitted or transported to other custodians or others outside the controlled arena. Custodians are also required to ensure that an individual's privacy and confidentiality are protected if the information leaves the province.

7. Disclosure by electronic means

Custodians must either obtain individual consent, or ensure that consent was previously obtained, before health information can be disclosed by electronic means. This provision was included in the Act as a means of providing individuals with some level of control over the way their health information is disseminated. It also recognizes that more and more patient information is being created and stored in electronic form. Before the Act is proclaimed, the definition of "electronic means" and the operation of this provision will be clarified.

8. Privacy impact assessments

Privacy impact assessments are a tool to allow custodians to review their authority for various actions, to compare options and to fully consider the implications of proposed actions on the privacy of the individuals they serve. Custodians are required to complete a privacy impact assessment when:

- a custodian plans to develop or implement a new administrative practice or a new information system
- a custodian plans to perform data matching with another custodian or with a non-custodian (data matching refers to the creation of individually identifying health information by combining individually identifying or non-identifying health information or other information from 2 or more electronic databases, without the consent of the individuals who are the subjects of the information)
- the Minister or the department of Alberta Health and Wellness plans to request other custodians to provide individually identifying health information.

In each instance, the privacy impact assessment must be prepared and forwarded to the Information and Privacy Commissioner for review and comment before the custodian implements their plans.

9. Notation of disclosure

When a custodian discloses a record containing individually identifying health information, the custodian must make a notation indicating what information was disclosed, when, why and to whom. Under the Act, individual Albertans have a right to access their health information, including information about the disclosure of their health information.

10. Offenses and fines

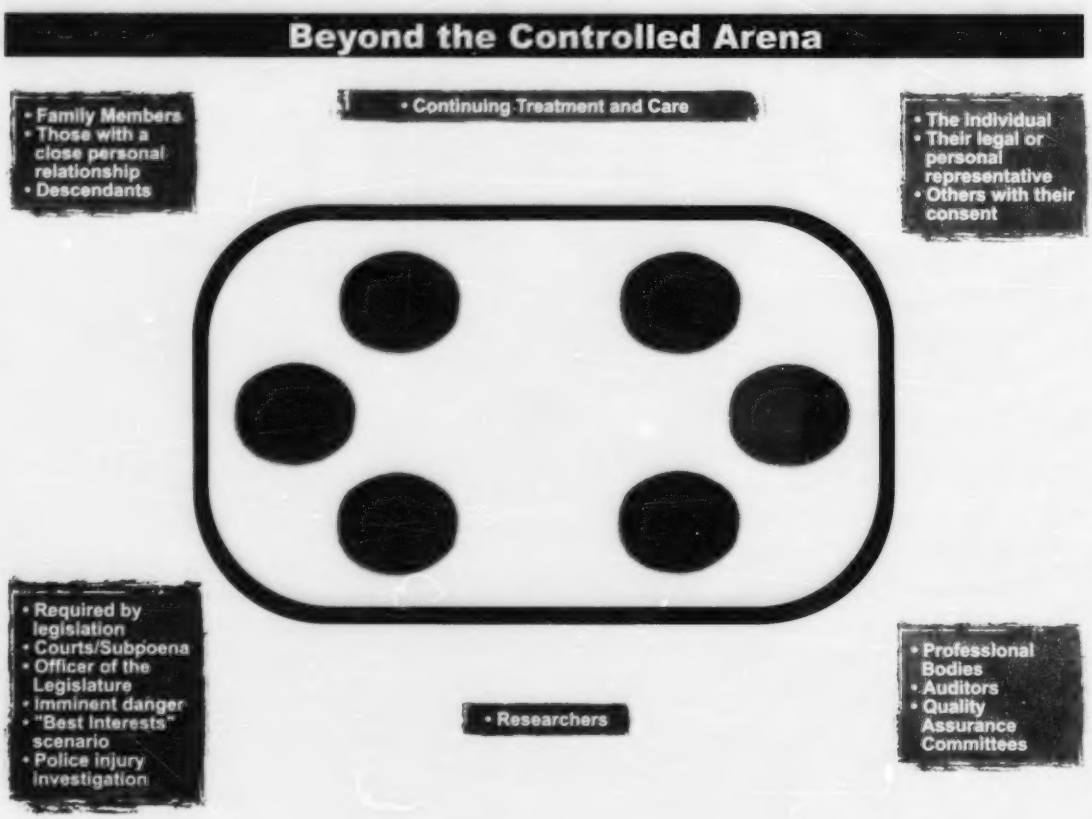
The Act sets out specific offenses such as gaining or attempting to gain unauthorized access to health information. In addition to the Information and Privacy Commissioner's powers to order a custodian to stop acting in contravention of the Act, and even to destroy health information collected or created inappropriately, custodians and others are subject to fines of up to $50,000. The area of fines, offenses and independent oversight is a significant deterrent to the inappropriate collection, use or disclosure of health information.

Checks and balances provide added protection

While any one of these barriers or obstacles may or may not adequately constrain a custodian's actions or protect the privacy of an individual, taken together, these barriers, along with the interplay between custodians, provide strong and adequate protection.

There also are important checks and balances all along the way. For example, before a custodian can inappropriately disclose health information, another custodian must also be willing to inappropriately collect that amount and type of information. Both the custodian disclosing and the one collecting are accountable for their actions to the Information and Privacy Commissioner and are potentially subject to significant fines under the Act. The likelihood of discovery of inappropriate actions is significantly increased both by the individual patient's right of access to the notation of disclosure information required under the Act and the protection offered to employees and agents of custodians. Employees and agents may inform the Information and Privacy Commissioner of any actions, by the collecting or the disclosing custodian, that are inappropriate under the Act.

What happens beyond the controlled arena?



In addition to the custodians that are subject to the Act, it is recognized that there are many other individuals and entities that create, maintain or collect information about an individual's health. As long as the information they seek or have is not health information as defined in the Act (i.e. information that is created within the controlled arena), the Act currently does not regulate their activity. Some of these individuals or entities may be subject to other legislation, such as the Freedom of Information and Protection of Privacy (FOIP) Act, or to other privacy related rules, such as practice guidelines or privacy codes.

There are specific instances where the Act does address information outside the controlled arena. Possible recipients of health information outside the controlled arena can be grouped as follows:

- **Continuing treatment and care providers** in the community, or not otherwise subject to the Act, may need information about a health service provided in a hospital or clinic setting to provide the best possible ongoing care to their patient.

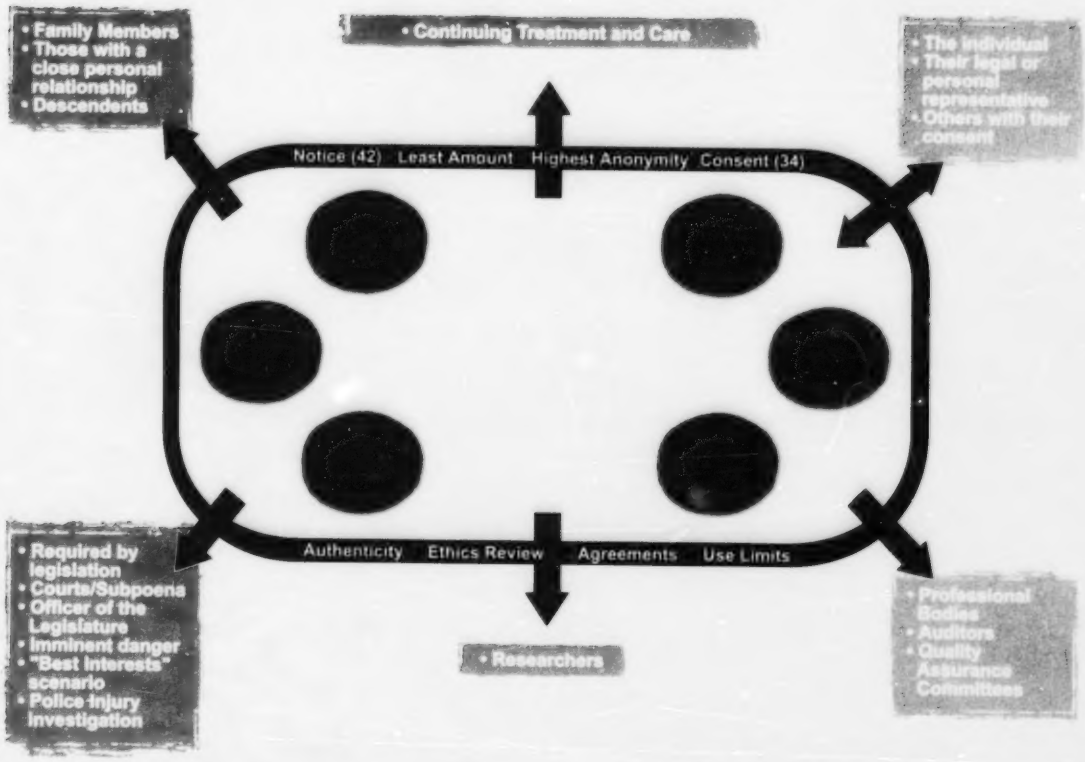
- The **individual**, the individual's legal or personal representative or others with the individual's consent may want some or all of the individual's medical record for various purposes.

- Those reviewing the actions of custodians or health service providers (i.e. specifically **professional bodies, auditors and quality assurance committees**) need some amount of information about health services provided to an individual.

- **Researchers** may need information about identifiable individuals but it may not be possible or feasible to obtain consent from each person in a study population.

- **Those requiring information** as outlined in other legislation, by the courts or in a subpoena, by an Officer of the Legislature (e.g. the Information and Privacy Commissioner) in order to perform their duties, by those who may be in imminent danger, by those who may be able to act in the best interests of a person who cannot act in their own best interests or by the police investigating a life threatening injury to the patient need some amount of information about identifiable individuals.

- **Family members**, those with a close personal relationship and descendents may need information if a person has been admitted to hospital, has died or if information about a deceased relative's health may help to resolve health issues facing the descendent.


• Family Members
• Those with a close personal relationship
• Descendents
• Continuing Treatment and Care
• The individual
• Their legal or personal representative
• Others with their consent
Notice (42) Least Amount Highest Anonymity Consent (34)
Authenticity Ethics Review Agreements Use Limits
• Required by legislation
• Courts/Subpoena
• Officer of the Legislature
• Imminent danger
• "Best interests" scenario
• Police injury investigation
• Researchers
• Professional Bodies
• Auditors
• Quality Assurance Committees

As the above diagram illustrates, before health information leaves the controlled arena it must pass through a "wall" or "membrane," which acts as a filter or barrier to the flow of information. Many of the same rules apply to disclosure of information outside of the arena as would apply to the movement of information within the arena. The custodian who has the information still acts as the gatekeeper of the information. The express informed consent of the patient or the subject of the information will still authorize the custodian to disclose information to a third party outside of the arena. The custodian must still consider the least amount of information at the highest degree of anonymity. The custodian must still protect or safeguard the information while it is in transit to the recipient of the information, even if that recipient is in another province or country. The custodian must still make a notation of the disclosure.

There also are additional requirements that apply to this type of disclosure. These include:

- **Notice of disclosure** – The custodian must notify the recipient about the custodian's authority to disclose the information and the purpose for which the information is being disclosed. This accomplishes two purposes. First, it ensures that custodians carefully consider whether they have the necessary authority to disclose information. Second, it ensures that custodians inform recipients of their legal authority and the purpose for disclosing the information. This purpose statement constrains those recipients that are bound by FOIP, professional guidelines, the CSA Privacy Code or other standards requiring limited or consistent purposes.

- **Authenticity** – The custodian must take steps to ensure that the person who will receive the information is the person intended and is authorized to receive it.

- **Research** – If the custodian is considering disclosure for research purposes, there is a requirement in the Act for the researcher to submit their project for review by an approved ethics committee and to comply with the requirements of the committee. If the committee agrees that disclosure can occur without the consent of the individuals, the custodian may disclose the information as long as the researcher enters into a research agreement limiting the use and disclosure of the information and requiring the researcher to adequately safeguard the information.

- **Limitations on use** – Recipients of health information are bound in three specific areas under the Act. They are prohibited from using the information for direct commercial marketing or fundraising purposes without consent. They may not take steps to re-identify an individual from non-identifying information without first notifying the Information and Privacy Commissioner. And they may not require a person to provide their Personal Health Number, unless they are on an approved list in regulation, and if they are allowed to collect Personal Health Numbers, they cannot use it for additional purposes.

In addition to those specific requirements, each of specific provisions in the Act that allow health information to move outside the controlled arena have additional constraints or limitations identified within the provision itself.

For more information ...

This document provides an overview of how the Health Information Act will work. Plans are now being developed to implement the legislation. Additional materials, training manuals, and public information materials will be available for all custodians.

If you have questions or would like more information, please contact:

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